

From **Social** Entrepreneurship to “**Cure** Entrepreneurship”

Meeting Report



From **Social** Entrepreneurship to “**Cure** Entrepreneurship”

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Hosted by

FasterCures
The Center for Accelerating Medical Solutions

Esquire

“ The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man. ”

GEORGE BERNARD SHAW

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I. Introduction

By Greg Simon, President, *FasterCures/The Center for Accelerating Medical Solutions*

FasterCures looks in small spaces for big ideas. The Redstone Acceleration and Innovation Network (TRAIN) is an affinity group we've assembled of unique nonprofit foundations that fund and conduct medical research across a spectrum of diseases, from breast cancer to Parkinson's disease. These organizations – such as the Michael J. Fox Foundation for Parkinson's Research, the Myelin Repair Foundation, and the Alpha-1 Foundation – have earned a reputation for taking new, more strategic approaches to conducting research in order to accelerate results. In some circles, these groups are becoming known as “venture philanthropies” – or as we like to say, sources of “passion capital.”

In the past, *FasterCures* has helped TRAIN groups look with fresh eyes at their relationships with other sectors such as philanthropists and industry. At this meeting – the latest in a series of annual events co-hosted by *Esquire* magazine – we asked them to step back even farther and think about their place in the larger universe of nonprofit social endeavor.

The field of **social entrepreneurship** has flourished over the last decade, attracting scholarship, media attention, and financial resources and building social and professional networks – as is evidenced by the success of organizations like Ashoka and the Skoll Foundation and the creation of curricula at business schools from Stanford to Harvard.

Medical research, however, is one area of nonprofit social endeavor that has been largely excluded from the dialogue and the discipline, with the notable exception of global health. Yet medical research philanthropy is seeking to address a market failure no less important than other social enterprises: the development of therapies that cure disease and alleviate suffering. Today's “**cure entrepreneurs**” – like the ones in TRAIN – are trying to leverage their relatively small dollars to help move promising research through the pipeline from basic discovery to commercial development of products that can help the patients they care about.



We need to create a functioning market for disease research in the nonprofit space, with enough data for investors to make smart decisions about where to put their money and ways for foundations to measure performance and outcomes. **Can we create an intersection between social entrepreneurship and medical research philanthropy – an ecosystem to support the work of cure entrepreneurs?**

Collaborative, mission-driven, results-oriented, and strategic in their use of capital, the nonprofit groups in TRAIN are motivated solely by moving promising therapies from the laboratory bench to the patient's bedside as rapidly as possible. This is perhaps the tie that binds social entrepreneurs and cure entrepreneurs most tightly – the bottom line that drives their actions and decisions is the health and well-being of individuals everywhere around the world, whether those mired in poverty or those suffering from disease.

FasterCures Founder and Chairman Mike Milken opened the meeting by talking about the current economic crisis and the premium it puts on social capital. He invoked the image of a community barn raising, saying, "The question today for me is, what barns can we build? What are we capable of doing?"



Mike Milken offers his opening thoughts.

"We have the ability to generate more value for the economy than any bank plan that you're going to read about in the newspaper today. We know that cures for cancer and heart disease are each worth more than \$50 trillion to the U.S. and more than \$100 trillion worldwide. So there is an economic message in everything we do."

At the beginning of this event, I made the comment that we weren't trying to get anywhere, we were trying to be somewhere, someplace new for most of the people in the room. We asked more questions than we answered. What we offer you here are some of those questions, the thoughts of meeting participants, excerpts of interviews conducted after the meeting with some of the key participants (and a few who couldn't make it), and a handful of resources that we hope are useful to those interested in helping us to build the field of "cure entrepreneurship."



Greg Simon kicks off the discussion.

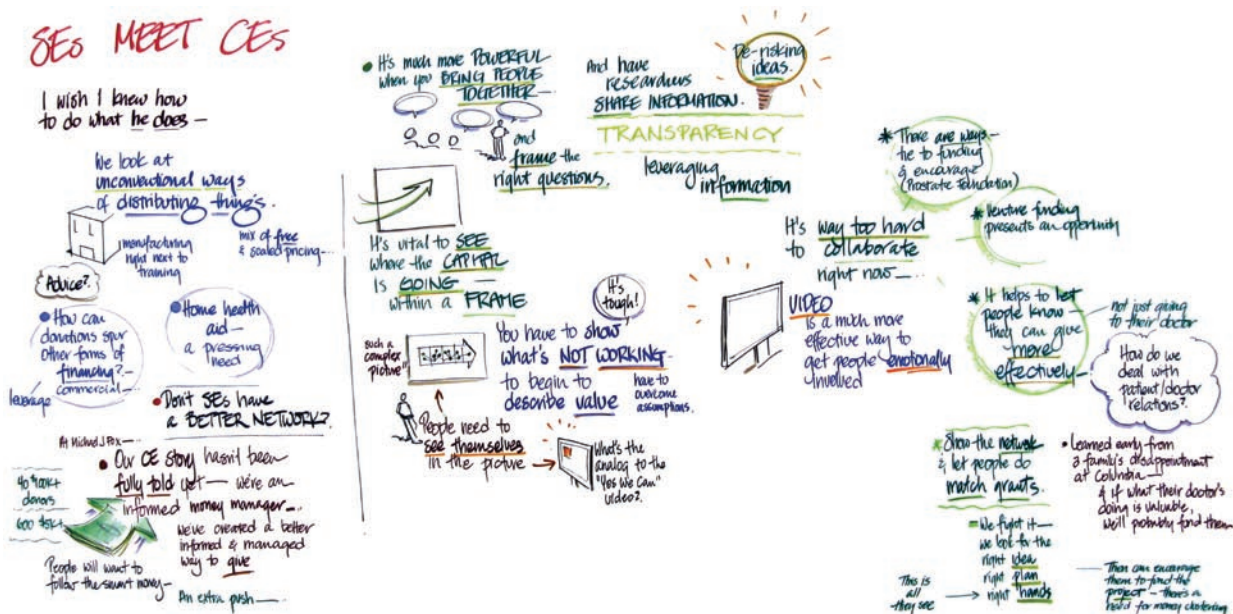
II. Social Entrepreneurs Meet Cure Entrepreneurs

Social Entrepreneurs

A lot of time and energy gets expended in the social entrepreneurship world debating the definition of the term “social entrepreneurship.” An important element is that it targets the needs of the “base of the pyramid” or BoP, the largest and poorest socioeconomic group – in global terms, the four billion people who live on less than two dollars a day.

Cure entrepreneurs often do not specifically target diseases that disproportionately impact the BoP. But for our purposes here, we would like to offer up a few definitions of social entrepreneurship that we found useful, because they embrace what many of the cure entrepreneurs are doing.

- “Social entrepreneurs are entrepreneurs, first and foremost; it’s just that their value propositions target neglected, disadvantaged or suffering segments of society.”¹
- “Entrepreneurs whose new ventures (social enterprises) prioritize social returns on investment, i.e. improving quality of life for marginalized populations by addressing issues such as health, poverty, and education... these people aim to achieve higher leverage than conventional philanthropy and NGOs [nongovernmental organizations], often aiming to transform the systems whose dysfunctions help create or aggravate major socio-economic, environmental, and political problems.”²
- “By social enterprise we mean the application of business models and acumen to address social issues, whether through nonprofit or for-profit corporate structures.”³



¹ Osberg, Sally. 2007. Skoll Foundation Foreword to *Growing Opportunity: Entrepreneurial Solutions to Insoluble Problems*, London: SustainAbility.

² SustainAbility. 2007. *Growing Opportunity: Entrepreneurial Solutions to Insoluble Problems*, London: SustainAbility.

³ Emerson, Jed, Tim Freundlich and Jim Fruchterman. 2007. *Nothing Ventured, Nothing Gained: Addressing the Critical Gaps in Risk-Taking Capital for Social Enterprise*, University of Oxford: Said Business School.

Arguably, the best-known example of a social entrepreneur is Nobel Prize winner Muhammad Yunus – who, along with many other ventures, founded the Grameen Bank. Yunus is widely held to be the “father” of microcredit, in which very small loans are extended to the poor to support

their businesses, and which has proven to be very effective both for the recipients and for the lenders.

We asked *Esquire* meeting participant Lucy Bernholz, Founder and President of Blueprint Research & Design, how social entrepreneurship is transformative and what its limits are.

nterview

Lucy Bernholz

Founder and President, Blueprint Research & Design

Social entrepreneurship pushes pretty hard on some traditionally significant walls. The essence of social entrepreneurship as I define it is bringing to a set of social problems not just the revenue-generating methodologies of commercial activity, but also the vision of the scope and scale of change that’s possible that entrepreneurs bring to creating commercial entities.

It’s a mindset, and there are also capital systems in place that facilitate that, and a cultural zeitgeist that facilitates that, and certainly global connectivity that facilitates that. So social entrepreneurship is both the application of commercial revenue-generating tools and methods, but also a fundamentally different sense of scale and scope – not that it’s always achieved, but it’s there at the start. And those who talk about supporting social entrepreneurship, some of them are quite active in trying to build those support systems, those financial systems, et cetera.

It’s transformative in that people go after bigger problems and they try to build enterprises that will be scalable to either defined problems on a global or at least on a much bigger scale, or they’re going after bigger problems. It’s transformative in that I think it fundamentally questions and comes up with a different answer than we’ve had about market forces and tools and where they fit in solving social problems.

There are a couple of very important limits to it. One is a lot of the social problems we’re trying to solve are actually the result of market failures. Microfinance is probably the social enterprise that’s taken off on the grandest scale and created the largest, most complex set of interconnected systems to support it. There are a lot of debates out there over whether or not it’s actually lifting anybody out of poverty. There’s a lot of concern, expressed notably by Muhammad Yunus himself, that because it’s a market-based set of tools, once it’s proven that revenue can be generated on top of the cost of providing the service, the market will come in, and profit-takers will not reallocate those profits toward the social good. So in fact you shift the market, you shift the problem, but you don’t solve the problem.

The market does some things well, the independent sector does some things well, and the public sector does some things well. And what we can be very creative with is how those things interact and to recognize that as any one of those three shifts, the others have to shift. Over the last 40 years those three sectors independently have done nothing but shift, but they haven’t necessarily coordinated the way they’ve changed their behavior with the other two.



Every year, *Fast Company* magazine recognizes nonprofits taking novel approaches to address market failures like pollution, poverty, and illiteracy with its Social Capitalist Awards. A list of the organizations that have received the award from 2004-2008 is in Appendix B.

One of the organizations *Fast Company* cites as a “Social Enterprise of the Year” for 2009 is the

Institute for OneWorld Health (iOWH), a “nonprofit pharmaceutical company” that develops new medicines for infectious diseases such as visceral leishmaniasis and diarrheal disease. We asked iOWH Founder Victoria Hale, who participated in the *Esquire* meeting, how being part of a community of social entrepreneurs has helped her do her work.

interview

Victoria Hale

Founder and Chair Emeritus, Institute for OneWorld Health

I’m asked when I’m interviewed, “Who inspires you?” And I say immediately, other social entrepreneurs. They’re not in my sector necessarily, but they can be, and they’re out there doing amazing things. Whoever would have thought we could tackle that problem that looks so big, but they really are. Whoever would have thought of that new approach, and it’s being done, not top down at all but working with communities to make it happen. Just so creative and unrelenting. Perseverance and persistence. We don’t give up, we try things and see what works and what doesn’t work.

Muhammad Yunus speaks in his book [*Creating a World Without Poverty*] about all of the Grameen corporations, nonprofits or for-profits, that he started and why some of them worked and why some of them didn’t. They’re all lessons along the road, and I am part of that community, sharing in those lessons and being with other social entrepreneurs as they’re on their journey.

I can learn more from a social entrepreneur that’s working on the environment or sanitation than I can from, let’s say, some other professionals in my sector or in the big pharmaceutical industry, in terms of changing the world and how to have an impact and how to make a sustainable business and how to mobilize communities. There are incredible people around the world who are doing this in other sectors.

We’re in silos in terms of the work that we do. If we have many silos within health and we aren’t learning as much from each other as we could, then can you imagine what we could learn from other social entrepreneurs who are working in social justice or women’s empowerment or education or water? These are incredible human beings who are on the same journey that we’re on, but the details are different.



Cure Entrepreneurs

The community of social entrepreneurs has long included organizations whose mission is to address the health needs of the global poor by focusing on overcoming the challenges of delivering existing or low-tech treatments, such as bednets to reduce the incidence of malaria. It has also come to include a number of organizations like iOWH, created to facilitate the development of new, high-tech drugs, vaccines, and other treatments for diseases of the developing world.

Born out of necessity – because industry had little incentive to invest in diseases of the global poor – innovators in global health are creating complex networks and cross-sector collaborations, combining the resources of government, academia, philanthropy, and industry in outcomes-driven efforts to move promising research through the development pipeline and out to patients. While many believe the differences between developed world and developing world disease research challenges are too significant to make for any productive conversation, we believe there are lessons to be learned from the global health experience by groups focusing on similarly neglected developed world diseases.

In a 2008 white paper, “Entrepreneurs for Cures: The Critical Need for Innovative Approaches to Disease Research,”⁴ *FasterCures* laid out many of the key issues affecting progress in the traditional medical research system and highlighted the critical role that philanthropic investment can play in addressing market failures that are preventing promising ideas from benefiting patients.

Our current publicly-funded academic research infrastructure has focused primarily on the earliest stage of research, or basic research; the biopharmaceutical industry funds primarily the latest stages of research, or clinical research. The result is an ever-widening gap – referred to by some as a **“valley of death”** – in funding and support for

the kind of translational research that moves basic science down the path toward treatments.

Free of the pressures of publication and career advancement in academia and the bottom-line imperatives of the private sector, nonprofit foundations with an entrepreneurial mindset are ideally positioned to make relatively high-risk investments that could significantly move a field of research forward and increase the likelihood that other parties also will invest.

At the November *Esquire* meeting, a conversation between two significant players in the academic medical research enterprise highlighted the extent of the challenges the traditional establishment faces in getting to cures faster and the need for new approaches to address the shortcomings of the existing paradigm.

“The Middle Is Empty Everywhere”

Greg Simon’s conversation with Lee M. Nadler, Professor of Medicine at Harvard Medical School and Co-Director of Harvard’s Clinical and Translational Science Center, and A. Stephen Dahms, President and CEO of the Alfred E. Mann Foundation for Biomedical Engineering



Lee Nadler and Steve Dahms discuss the challenges facing disease research.

⁴ Available at http://fastercures.org/objects/pdfs/white_papers/FastercuresWP_Innovation_052808.pdf.

Nadler:

Over the last 30 years that I've worked in the area of what we'll call translational research to clinical investigation, I see the pipeline getting smaller and smaller, not bigger and bigger, even though the discoveries and the knowledge grow.

I work for a pretty big place called Harvard, which is a bunch of individual academic healthcare centers all standing on their own bottoms at a very large university. No one knows what is in that treasure trove. Our technology transfer offices don't know what we do in our laboratories. We walk around every day and discover these amazing things, and yet they are all hidden. So for me the challenge for patients and for scientists is communication. The information is not available. It is not available to you what is going on, it's not available to the tech transfer offices, and it is certainly not available to industry.

I ran a department that had 180 faculty and 1,500 people, and I didn't have a clue what they were doing because there was no way of knowing. We always said the lights never turned off at Harvard.

This valley of death – I don't actually think the structures to solve that exist anywhere. We need something different. The basic scientists are incented and will do what they do, they will do basic science. And the clinicians who actually do experiments in human beings – not that very first one, not that breakthrough one – those people will do the clinical trials for the pharmaceutical industry. **But the middle is empty. It is empty at Harvard, it's empty at Stanford, it is empty everywhere.** I don't think one university can do it. I think we need a national approach to this. We need collaboration.

Dahms:

This year about \$50 billion of research will be conducted in U.S. universities. And out of that will come something around 2.8 percent of a return on the investment – the return on investment to the taxpayer that is subsidizing it, the return on innovation, the return to the patient. There are not enough good ideas getting out there.

We think the technology transfer process at universities is broken and not working. I think we need a different way of moving the university ideas forward in a way that benefits mankind. Our model [at the Foundation] is designed to create institutes at universities that are evergreen, that move the university intellectual property up the value chain while the university still owns it. They will spend upwards of \$150,000 to validate the project before it moves; universities spend \$2,000 or \$3,000 max.

Company spinouts as the exit strategy for university intellectual property that is eventually going to benefit mankind may not be a valid mechanism. Company spinouts is not really the ultimate benchmark. It's the benefit getting to society and to the patient.

Nadler:

One of the great things that can come out of this meeting is a concept for a new model, a new model for how to do this. I want Harvard not to benefit ultimately from intellectual property. I want people to invest with us up front. Let us do the work and not ask for any return on investment at all, because the government paid for it anyway.

Dahms:

There is one credible individual that says in the next 40 years, U.S. private foundations will be pitching out over \$50 trillion. And the question is, how will these foundations be redirected in a way that mirrors the interest of faster cures?

"As I transitioned from the for-profit to the not-for-profit world, it was incredibly frustrating and maddening for me to find the level of in-fighting that goes on between NGOs and scientists. It was completely shocking. I think it's almost easier in the for-profit world, because at least you know what the other person's motivation is."

MELODIE HOLDEN, SENIOR VP | VENTURE STRATEGIES



Disruptive Innovators

For purposes of the *Esquire* meeting, we laid out some of the similarities and differences between social entrepreneurs and cure entrepreneurs (Figure 1).

One of the striking similarities between the two groups is that, while they are both often focused on innovative products (new drugs, new technologies to improve the lives of the global poor, new approaches to education or job training, etc.), they are also importantly focused on innovative processes and business models.

Deborah Brooks, Co-Founder of the Michael J. Fox Foundation for Parkinson's Research (MJFF), noted at the meeting that many philanthropists don't understand why they should give to a grantmaking intermediary like MJFF when they could give directly to a researcher or an academic institution. But an effective foundation like MJFF adds value to the scientific enterprise by building a comprehensive view of the entire Parkinson's research landscape, placing well-informed bets on where the most promising research is being done, and bringing a level of coordination and management to the scientific process.

Figure 1: Social Versus Cure Entrepreneurs

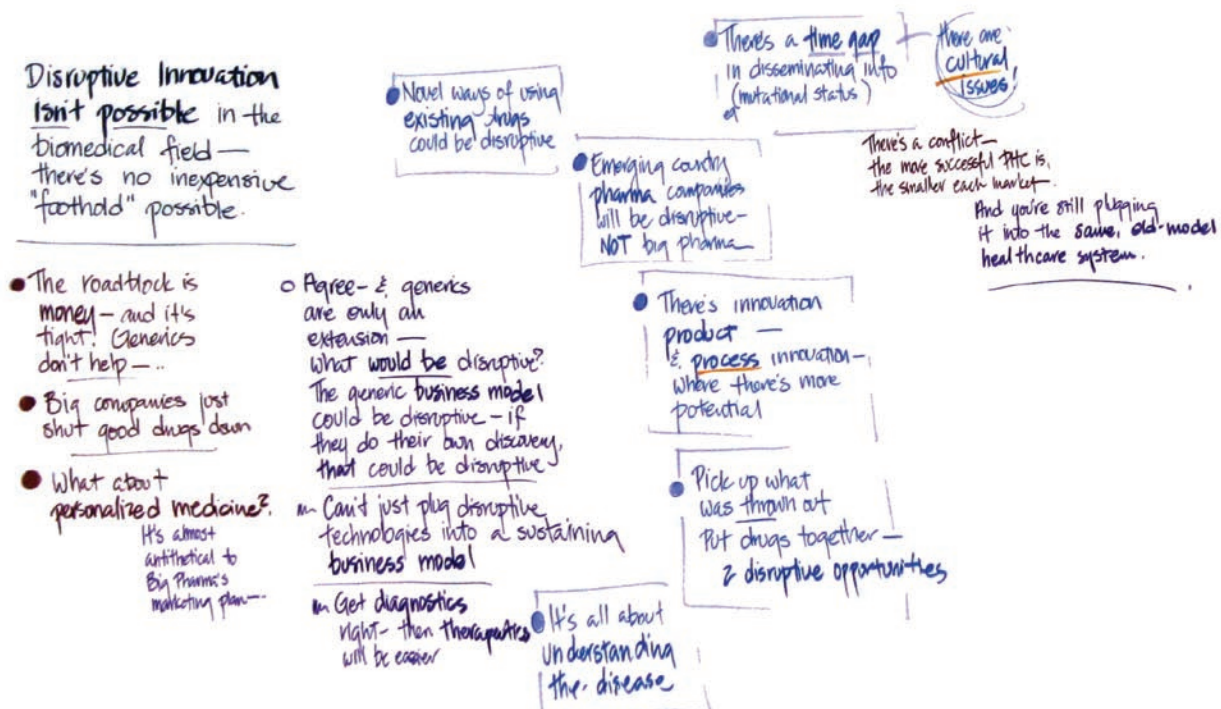
Social and cure entrepreneurs share many of the same goals and qualities:

- Driven by mission to more strategically address a market failure with social consequences
- Motivated to challenge existing culture/paradigm
- Often individuals with a business/entrepreneurial background
- Perceive the need to experiment with new funding models
- Interested in measuring and maximizing performance of investments
- Interested in leveraging greater investment by other stakeholders

But there are differences that need to be acknowledged:

	Social entrepreneurs	Cure entrepreneurs
Scope of mission	Varying definitions, but generally address needs of the poor and disadvantaged globally	Discovery & development of treatments for diseases of developed and developing world
Definition of entrepreneur	s.e. is on frontlines delivering services	c.e. is intermediary organization, funding front-line researchers
Cost/risk/timeline of activity	Can be low cost, short-term	Therapy development very expensive/risky, long-term
Commercial nature	Variety of nonprofit/for-profit scenarios possible	For-profit entity almost always needs to be involved at some point

Source: FasterCures analysis



“We are like an informed money manager; we know all the stocks, when to buy, sell, or hold,” she said. And she noted that “companies are effectively outsourcing early-stage research to us,” because the foundation can fund research that helps them make better-informed decisions about making follow-on investments in Parkinson’s products.

This discussion of products versus process fed right into an impromptu debate at the meeting about **disruptive innovation**, a theory developed by Harvard Business School professor Clayton Christensen, represented at this forum by his colleague Jason Hwang.

Christensen and Hwang distinguish between two types of innovation: sustaining and disruptive. Most of what companies consider “innovation” is of the sustaining variety – that is, “the continual improvement of a product or service that is introduced by companies over time. ... Sustaining innovations result in better products that can be sold for higher profits to the best customers.”⁵

Disruptive innovation makes complex and expensive products and services more affordable and accessible. An example they frequently cite is the introduction of the minicomputer, which manufacturers of expensive mainframe computers were not interested in producing. “Because disruptive products do not appeal to the best customers paying the highest prices, they are almost always introduced by new entrants rather than the dominant incumbents of an industry.”⁶

As Hwang pointed out at the meeting, disruption “is not just a technological problem – it’s a business model problem.” While a “technological enabler” is necessary for disruptive innovation, it’s not enough to have a really novel product. Also required – and perhaps more important – is a business model that brings together the resources required to deliver the “value proposition.”

In a subsequent interview, Hwang offered his insights into how patients and patient-driven organizations could play a role in disrupting the current therapy development paradigm.



Deborah Brooks points out the important management role nonprofits play.

⁵Hwang, Jason and Clayton M. Christensen. 2008. “Disruptive Innovation in Health Care Delivery: A Framework for Business-Model Innovation,” *Health Affairs*, 27(5).

⁶Ibid.



“I think that the NIH and a lot of patient organizations do not start out with a plan. Look at this house that we’re sitting in. Can you imagine if we used an RFA [request for application] process to build this house? We would have no toilets, a lot of showers, and the bedrooms would be outside. It’s a culture that makes me crazy. We need more strategy and focus and direction.”

NORMAN SCHERZER, EXECUTIVE DIRECTOR | LIFE RAFT GROUP

nterview

Jason Hwang

Director for Health Care, InnoSight Institute



I mentioned earlier this idea of the facilitated network, where basically patients are helping patients. Now you're seeing these new business models like Patients Like Me, where you have like-minded patients in similar circumstances who are getting together to share their most personal details about their conditions, how they treat themselves, and who are basically sharing advice with one another.

It's very much the type of model that we would see in any network business, like eBay or Facebook. That presents a unique opportunity for how they can be incorporated into our processes of biomedical research. There are some obvious ethical challenges, but there was a great case of motivated ALS patients on Patients Like Me who basically ran their own clinical trial. They did so not because they had any sort of death wish, but because this was a trial that no drug company would ever want to fund. It was too small of a patient population, not enough income potential, and not enough data to support it over other higher priority clinical trials. But to them it was a high priority.

The results did not pan out as they thought, as it turned out to be a negative trial. But it was an example of patients being able to take over more control of something that otherwise the current system is not giving them. That's almost the very definition of the "non-consuming" population that we often describe as the perfect place for disruptive innovations to arise.

A non-consuming population is basically one that is not privy to current products and services in the marketplace, either due to expense or a lack of expertise. That's very much the case in healthcare where you might have a lack of insurance or you don't have enough knowledge to care for yourself, and there are strong parallels to every other industry that has been disrupted.

In the old days of computing, most people couldn't operate a mainframe on their own -- they had to seek out an expert to help them. And nobody could afford a mainframe; only large corporate centers or universities could afford mainframe computers. So there were large numbers of people excluded from computing services, at least until the PC disrupted the computing industry. You see these parallels across the early stages of every industry, but these issues of cost and accessibility are ultimately resolved through disruption.

I think the same transformation will occur in healthcare, where you get this increased democratization and decentralization of products and services in the healthcare market. And the demand for disruption in healthcare will be driven by patients who feel ignored by the current system.

Q: Do you think that it's possible that nonprofits that fund medical research could be a catalyst for disruptive innovation in the biopharmaceutical industry? Do you have any specific ideas for groups in that situation about where they ought to be focusing their resources?

A: The perspective that a nonprofit foundation or philanthropic organization carries is really no different from the perspective of, say, a VC or an internal corporate investment arm, because essentially the job that you're trying to fulfill is to create value in the long term. That involves examining profiles of potential projects and placing bets. In the VC world and in the world of any of these players, if you bat one out of ten you're probably doing a decent job. But our theories tell you that there's greater predictability there. If you apply our theories and you invest in a mixture of sustaining and disruptive products tailored to what your long-term goals are, you can do a much better job in terms of success rate, simply because you'll be able to identify and invest in disruptive ideas that are the seeds of future market growth.

Regarding the biopharmaceutical industry in particular, perhaps the most important thing nonprofits can do to encourage disruptive innovation is to constantly seek perspectives from beyond the existing expertise within the industry. We've observed that disruptive ideas most often come from the intersection of disciplines, and rarely does a truly disruptive idea arise from the process of "normal science." But most of the world's investment in R&D has been focused on incremental knowledge building. In fact, the common process of peer review in research, our traditional silos of scientific disciplines, and the overwhelming need of companies to fill their dissipating product pipelines are all in fact impediments to paradigm-changing research. However, if nonprofits start with a broader perspective to solving challenges in the biopharmaceutical industry, I think there is much greater hope for their investments to catalyze real breakthrough innovations.

III. Building Intellectual Capital, Attracting Financial Capital

Building a Field

Lucy Bernholz has been thinking recently about field-building. She summarizes in her blog “Philanthropy 2173” what she’s learned about what’s needed to take a field from “a phase of entrepreneurial fragmentation ... to organized markets: infrastructure, intermediaries, networks, and standards.”⁷

In our interview with her, Bernholz emphasized the importance not only of doing the work that social entrepreneurs do, but of building the field:

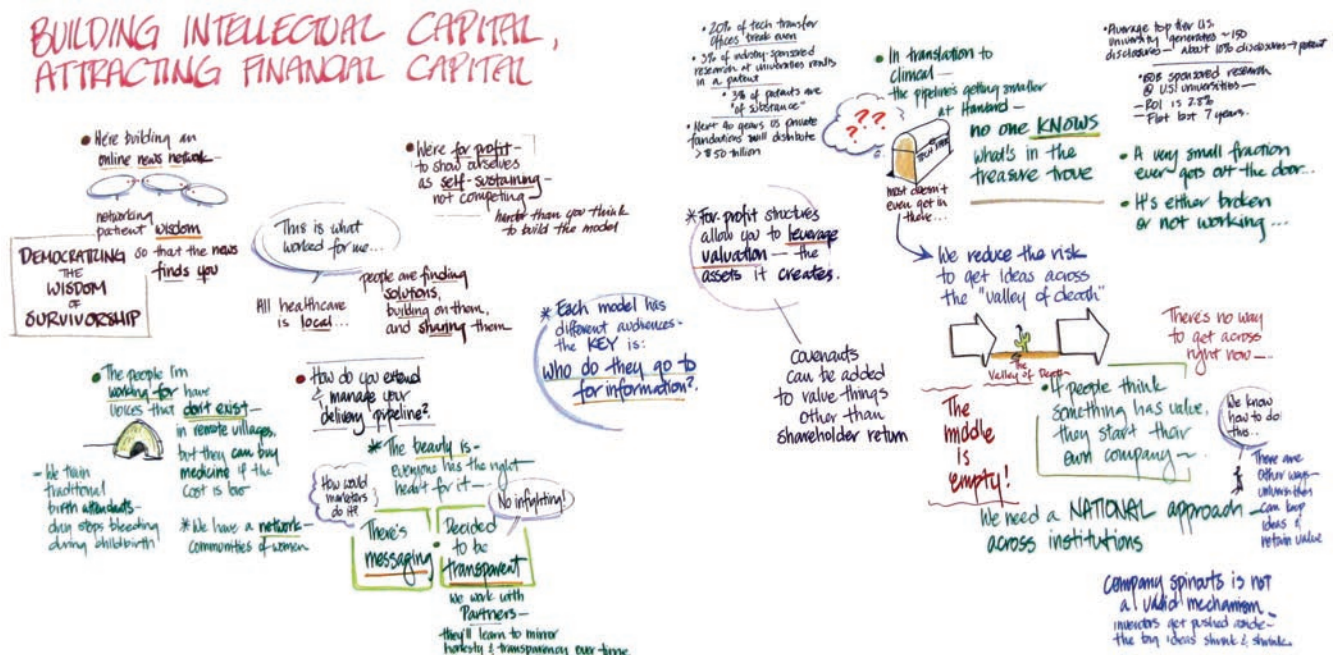
“What makes a group of like-minded organizations doing like-minded work more than a group of like-minded organizations doing like-minded work?”

“There’s the potential for having real policy implications. There’s the need to be able to name something in order to advocate for it. There’s the need to be able to name something in order to be able to defend it. There’s the need to be able to name something in order to build a pipeline of people

who will prepare to do that work, and then change the incentives of the institutions that prepare those people, universities and others.”

A field has certainly grown up – or been built up – to support the needs of social entrepreneurs. In Appendix C we have included a small sampling of organizations representing the depth and breadth of the human, intellectual, and financial capital that is being brought to bear on social enterprise.

Financial capital comes from prominent foundation funders like the Gates Foundation and the Schwab Foundation, and from a growing cadre of investment



⁷ <http://philanthropy.blogspot.com/2009/02/field-building-does-field-matter.html>

funds that expect some combination of financial and social returns – organizations like Acumen Fund, the Calvert Social Investment Fund, and New Profit, Inc. Online giving marketplaces such as Kiva and GlobalGiving allow small-dollar individual donors or lenders to find social ventures that they want to support and to aggregate the impact of their investments. Market intermediaries such as Altruistic Exchange and Xigi.net are seeking to create a “stock exchange” for the social capital market.

Consulting firms such as FSG Social Impact Advisors, Monitor Institute, and SustainAbility help social entrepreneurs with strategies and organizational problem-solving. Performance measurement tools are being developed by efforts such as the Keystone initiative and Acumen Fund’s Pulse system. Academic institutions and think tanks devoted to the study and advancement of social enterprise abound, from the Center for the Advancement of Social Entrepreneurship (CASE) at Duke University to the Social Enterprise Initiative at Harvard Business School.

Communications outlets such as the Stanford Social Innovation Review and socialedge.org provide

visibility to the work of social entrepreneurs, as do large-scale events such as the Skoll World Forum and the Social Capital Markets conference. And membership associations like the Social Venture Network and Business for Social Responsibility provide opportunities for networking and collaboration.

This is the rich soil in which the ecosystem of social entrepreneurship is rooted.

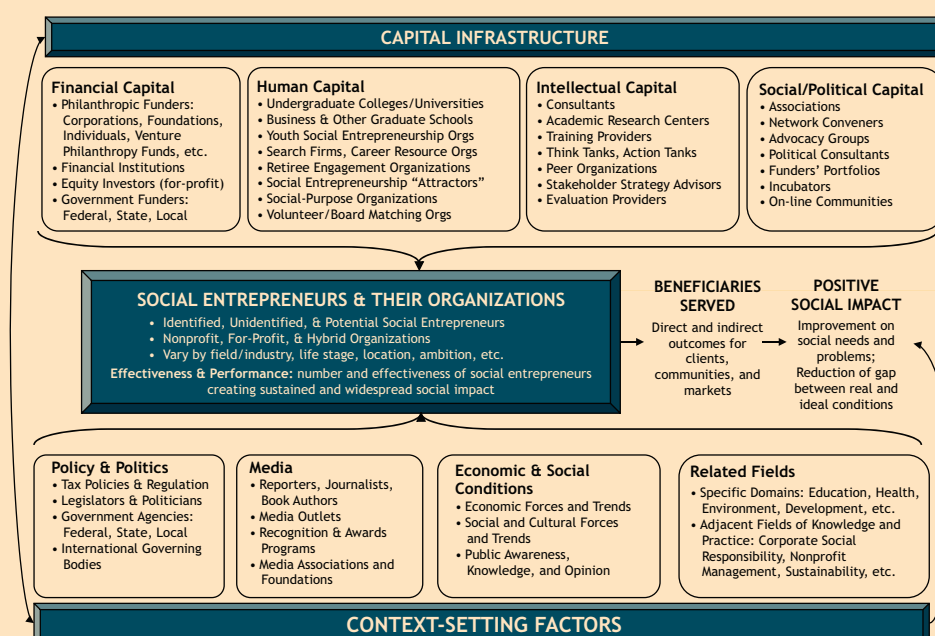
In its report “Developing the Field of Social Entrepreneurship,”⁸ CASE provided the graphic in Figure 2 to lay out all the elements of this ecosystem, along with some examples of each.

The CASE report identified five high-priority opportunities for improvement in this ecosystem:

- making **financial markets** more efficient and responsive;
- refining and standardizing **performance measurement** tools;
- helping social entrepreneurs find effective pathways for **scaling impact**;
- building appropriate **talent pipelines**; and
- providing better guidance on **sustainable business models**.

⁸Center for the Advancement of Social Entrepreneurship. 2008. *Developing the Field of Social Entrepreneurship*, Duke University: Fuqua School of Business.

Figure 2: Ecosystem of Social Entrepreneurship (with Examples)



Source: *Developing the Field of Social Entrepreneurship*, Duke Fuqua’s Center for the Advancement of Social Entrepreneurship (CASE)

These are certainly challenges that most cure entrepreneurs would recognize, and they could benefit from – and contribute to – the intellectual capital being brought to bear on addressing them in social entrepreneurship.

Developing Disruptive Business Models

Perhaps the thing that most distinguishes social entrepreneurs from others who pursue social goals is their experimentation with new business models and innovative financing models. This is certainly of interest and concern to the cure entrepreneurs, who are faced with a medical research process that is extraordinarily costly, usually funded and conducted by multiple parties (government, nonprofit, industry), and weighted with intellectual property considerations.

In their book *The Power of Unreasonable People*⁹, John Elkington and Pamela Hartigan identify three business models that social entrepreneurs tend to adopt.

- **Leveraged nonprofit ventures** address types of market failure that are “difficult – if not impossible – to tackle using for-profit business models...The key is to leverage available resources in ways that measure up to the nature and scale of the challenges...But nonprofits can be much harder to scale than for-profit ventures.”
- **Hybrid nonprofit ventures** offer the most opportunity for experimentation, the “imaginative blending of nonprofit and revenue-generating for-profit strategies” that can “produce unexpected forms of hybrid vigor.”
- **Social business ventures** are “for-profit entities focused on social missions” that seek out “investors interested in combining financial and social returns.”

The enterprise’s financing – and scaling – opportunities can be significantly greater because social businesses can more easily take on debt and equity.” Elkington and Hartigan note that these social businesses, “many of which first appeared outside the United States, may have evolved as an interesting but unintended by-product of the smaller philanthropic funds available to social entrepreneurs in other countries.”

At the *Esquire* meeting, Institute for OneWorld Health founder Victoria Hale advocated for rethinking the traditional financial model for developing drugs – for diseases of the global poor and for rare and neglected diseases of the developed world. In a subsequent interview she appealed for the growth of what she calls the “blurspace” between nonprofit and for-profit pharmaceutical development.

“I think the health space is in some ways a skewed base to look at, because the R&D costs are high. It takes a long time and there are failures. But we also haven’t been nearly as creative as social entrepreneurs working in other sectors. If we are able to complicate that space in between, and have for-profits that are driven by a social mission, or nonprofits that bring back revenue and are sustainable – I wish we had a third category or five categories that we could work through and wouldn’t be limited to one or the other. I think it’s coming.”

A pioneer in the development of disruptive business models to help bring high-tech therapies to the global poor is David Green, a Vice President at Ashoka and a MacArthur Fellow. In 1992, Green directed the establishment of Aurolab (India), the first nonprofit manufacturing facility in a developing country to produce affordable intraocular lenses (IOLs), sutures, pharmaceuticals and eyeglasses.

⁹ Elkington, John and Pamela Hartigan. 2008. *The Power of Unreasonable People: How Social Entrepreneurs Create Markets That Change the World*, Boston, MA: Harvard Business Press.

“It’s easy to give lip service to building a social business model, but it’s harder than you think in the healthcare space, because of the combination of social mission and the amount of money that exists in the space.”

CAROL LIN, CEO | TULAHEALTH



Aurolab is one of the largest manufacturers of IOLs in the world, with sales to more than 100 countries.

He is now developing a company to make hearing aids available and affordable via social enterprise channels in developing countries.

In addition to establishing medical manufacturing, Green has helped develop high-volume, quality eye care programs that are affordable to the poor and self-sustaining from user fees. He helped develop Aravind Eye Hospital in India, which performs

300,000 surgeries per year, making it the largest eye care system in the world. Seventy percent of the care is provided free of charge or below cost, yet the hospital is able to generate substantial surplus revenue. Green has replicated this cost recovery model in almost a dozen countries around the world.

In an interview after the *Esquire* event, Green described an innovative “concessionary fund” he has established to invest in eye care research and proposed it as a model for nonprofits funding disease research in the U.S.



Interview

David Green

Vice President, Ashoka

I brought together the International Agency for the Prevention of Blindness [IAPB], a consortium of eye care groups, with Deutsche Bank. We worked together to create debt financing for eye care and also grant funding to provide sustainability planning and technical assistance to some of our borrowers and also to programs ripe for becoming self-financing from user fees. Hopefully that fund will close by the end of March. It'll be about \$18 million in debt financing, six investments, and then we've raised \$1.6 million in grants that will provide sustainability planning – the clinical, surgical, managerial, outreach, business planning to make programs self-financing, but with the model where they serve lower income strata also.

IAPB has maybe 100 members. The members could come together and, instead of competing with each other for grant money, they could collaborate to put together enough deal flow – by deal flow I mean investing pull – to be large enough to look interesting to Deutsche Bank.

Deutsche Bank was interested because they had done a lot of microfinance fund development, and they wanted to see if they could go beyond microfinance and demonstrate social investing in another arena. It was very challenging for them, because microfinance has a very high rate of return, whereas this fund won't.

The idea is to use low-cost or no-cost money to reduce risk in order to leverage other investors. For the eye fund I told Deutsche Bank, you have to invest and take as much risk as you can. For this fund they'll be the first-loss cushion investor. They'll take the hit on any losses up to the amount they invested. That then reduces the risk for the next layer.

When you think about all the groups that were at the *Esquire* meeting, the question is, how many of them are investing in research that can ultimately generate earned income or become a product in a real company?

They provide money but then, because they're nonprofit, they don't always have the mentality of how they value the asset that they're investing into. And they don't have the mentality of how they control that asset to good effect for their own benefit later on, for benefiting their cause.



Let's say you take 20 organizations involved in trying to bring about cures. Each one of them has maybe 5 percent or 10 percent of what they're investing in that looks promising. That becomes an investing pool – it's like all of them collectively create a fund.

You have some financial institution, like Deutsche Bank, as the intermediary to organize and set up the fund and manage the various risks, the legal and fiduciary risks of the fund. Let's say you go after investment from larger foundations. A lot of foundations are looking to make program-related investments or mission-related investments¹¹. More and more are wanting to do that.

You can make it like a private equity fund with the social mission of cure. The type of investors that you bring in want to have both social and financial return. They, in effect, will have ownership of the intellectual property that emerges. You have to look at how to structure that so that there's a moment of liquidity for the fund, because that's what is really hard to do on the social side, is a moment of liquidity.

The nonprofit world, because it's nonprofit, does not get to benefit from leveraging off of increasing valuation of an asset. That's how the world works. That's how everything works. The social side and the nonprofit world has so many valuable assets, particularly the groups you're working with. I mean, what's more valuable than a real cure for a disease that was intractable before? There has to be a restructuring of how these entities house their assets so that they can get the benefit of being able to leverage off of increasing valuation. There are so many companies out there, that's all they do is value assets, whether it's for selling shares or whether it's for tax purposes or whatever. There's a whole industry involved in valuation.

Let's take Parkinson's disease, the Michael J. Fox Foundation. They have all this value. They have core competency in how they identify the right investments or places to put their money to bring about a cure. That's worth something. That needs to be valued. Nonprofits don't realize how much value they have in their knowledge base for placing the right bet.

Maybe some companies might even be investors in this fund, because they want in. They want to be able to have a new way of seeing and touching new deal flow, new potential product coming into their pipeline. But the fund is run with both social and financial return, where investors agree to covenants about the use of IP that pops from the fund. How do you have the right control of the IP to ensure that it reaches people who won't necessarily be able to afford it?

¹¹ According to Foundation Center, "Program-related investments (PRIs) are investments made by foundations to support charitable activities that involve the potential return of capital within an established time frame. PRIs include financing methods commonly associated with banks or other private investors, such as loans, loan guarantees, linked deposits, and even equity investments in charitable organizations or in commercial ventures for charitable purposes." <http://foundationcenter.org/getstarted/faqs/html/pri.html>. Mission-related investments are investments of a foundation's assets in ventures - charitable or not - that relate to the foundation's mission.

Social enterprise pioneers Jed Emerson, Tim Freundlich, and Jim Fruchterman have written that "there is a rich landscape of actors and strategies in the capital markets serving social enterprise, yet a significant gap remains in the availability of risk-taking capital to fund the expansion of promising organizations. ...this work requires a rethinking of capital investing and enterprise development. This includes the need for us to advance a broader understanding of the full, blended value [social and economic] created by capital and brought to market by ventures of all types—nonprofit and for-profit."¹²

It would be difficult to say that there is a rich landscape in the capital markets serving nonprofit disease research in the U.S. Are the financing models being developed in the social enterprise universe applicable to the needs of the cure entrepreneurs?

One thing is certain: there is an urgent need for more creative thinking about and models for financing large, high-risk, long-term investments that could lead to biomedical breakthroughs (including within the biopharmaceutical industry) – or what Emerson et. al. might call "the missing links between mainstream investing and traditional philanthropy."¹³

¹² Emerson, Jed, Tim Freundlich and Jim Fruchterman. 2007. *Nothing Ventured, Nothing Gained: Addressing the Critical Gaps in Risk-Taking Capital for Social Enterprise*, University of Oxford: Said Business School.

¹³ Ibid.

IV. Measuring, Maximizing, and Marketing Progress

Information Is the Scarce Resource

Another area in which social entrepreneurship is challenging traditional philanthropy is in the area of evaluation. Perhaps because social entrepreneurs aspire to apply business acumen to social issues, they tend to be more focused on measuring outcomes and auditing their performance – their “return on investment.” A better understanding of the impact their dollars have is also helpful in marketing their efforts to prospective donors.

Key to measuring, maximizing, and marketing progress are better information sharing among all the stakeholders and new tools for doing so.

FasterCures has often said that **the scarce resource in medical research is neither money nor places to invest it; the scarce resource is information.**

At the *Esquire* meeting, there were animated exchanges about the challenges and opportunities of information sharing at all levels.

Patients need information about options.

Researchers need information about others’ work, across institutions, across disciplines, and across diseases. Foundations and philanthropists need information about where to find the best ideas.

John Wilbanks, Executive Director of Science Commons, summed up the need for a “knowledge commons”:

“By having an incoherent information and knowledge space, the scientists don’t have good access to it, so they eliminate all the confusing information and focus on the smallest possible question, then get a yes/no answer for it. The funder doesn’t know what’s two steps out in a similar but related disease. The Huntington’s disease folks, in order to find out what the ALS folks are doing, have to schedule a meeting. That’s sort of ridiculous given the information space we’ve got. The third layer is that the clinician cannot access that incoherent information space, because the clinician is busy seeing patients. Fourth, the patients can’t access the



"It isn't just having all this information and all these people collected. It has to have some degree of collective intelligence, so that some of those tools that are used for Amazon.com are used for Parkinson's."

JESSE DYLAN, DIRECTOR/PRODUCER



information space. As funders, researchers, clinicians, and patients add content, those themselves now form silos that are not accessible to the other. And then at each of these levels you have a series of legal, technical, and social barriers, which can primarily be addressed by funder policy and standardization. They could actually begin to build some tendrils across those silos and let the networks begin to emerge.

"Everyone has recognized the power of building their own community where they share within the organization; Mike [Milken] referenced it in prostate cancer, Debi [Brooks] is doing it at PD Online, the Cure Huntington's Disease Initiative folks have built a fully integrated virtual biotech for Huntington's. But they look like walled gardens in the early days of the Internet. They look like AOL and CompuServe, but they don't connect.

"So there's none of that 'a-ha' sharing stuff where research is being done on infectious diseases in one place that triggers pathway information – it doesn't automatically flow and show up in the RSS reader of the person who's working on malaria. One of the things we're trying to do with some of the people building [PD Online] is to make sure they use the same names for things that they use in Huntington's disease. Because then it snaps together. You don't have to think about interoperating with the Web."



John Wilbanks talks about breaking down information barriers.

At the *Esquire* meeting, Greg Simon discussed with Lucy Bernholz the critical need for "reengineering the knowledge base" – the creation of more transparent information about who is doing what in the nonprofit space and the results that are being produced.

"The information about what might work to solve a problem may exist, but it's locked up, it's proprietary. Nothing should be proprietary in philanthropy.

"I often say philanthropy is the one place where we ought to encourage collusion. If we figure out what works, then let's share it.

"What is that continuum of options? Who are the organizations doing the work? What is the capital that's available? One of the most important things that will become visible in a picture like that is where all the gaps [in research and funding] are.

"The real barrier to getting folks to share that information is that they think it's garbage. They don't have any quality control. They're not sure it's any good, and nobody wants to go public with their strategy, their theory of change, their 'Yes, I've put \$10 million down this pipe but I don't actually know if it's the [right] pipe.' But if we can make visible, starting with those who have in fact invested in a strategy and a theory and a chosen set of organizations, and said 'This is where we're making our bets, and here's the evidence upon which we're basing that' – you can begin to change that culture, which I think is as much needed as funders requiring that people get together and share information.

"[A group like MJFF], you really do add value to a donor who can now leverage your entire mezzanine view of the field. You know the world of research. You know who's doing what. And that idea might not be ready this year, it might be ready next year.

“The key to philanthropy, the key to solving any of these problems is figuring out how to use each of your organizations to actually leverage other people’s money, not the money you’ve raised but other people’s money, particularly for private foundations.”

Betsy Zeidman, Director of the Center for Emerging Domestic Markets at the Milken Institute, chimed in with her observations about information sharing:

“The area that I work in is almost exclusively economic development and finance. But we have very similar issues, because you have huge data sets. How these loans did, how things performed, how these grants did? Everybody has a different data set. We have been working very hard to try to get these things to collaborate. But there’s a lot of organizational disincentives to doing so. They want to stake out

their claim about what makes them different so that they can go out and raise money for what they are doing and make sure that it’s just a little bit different than what this one’s doing, because there is a fairly limited pool of capital. So it seems to me that part of this issue is how do you overcome those barriers, the institutional, structural disincentives to sharing?”

Creating New Information Marketplaces

One important effort to create a tool for both measuring the internal performance of nonprofits and allowing them to benchmark their work against that of peer organizations has been initiated by the Acumen Fund, a leading social investment fund. We interviewed Brad Presner about Acumen’s Pulse system, created for its own use but now being opened up to the community of social investors and entrepreneurs.

nterview

Brad Presner

Metrics Manager, Acumen Fund

The intent of Acumen Fund was to make investments in small and growing businesses in the developing world that provide a social good. So it’s essentially a social venture capital fund. We find early-stage entrepreneurs and provide them with debt or equity investments. We accept less than market financial return because financial return is not our sole motivation. There’s a lot of discussion about the social returns. What are they doing, and who are their customers? Part of our due diligence process is that we want the company to have a very significant portion of their target customer base be people living on two dollars a day or less.

Our portfolio team needed a more scalable, generally acceptable means to track their performance on whatever the social metrics were for a given investment against their targets.

So let’s say we’ve made an investment in a company that produces bed nets, and their main output is to create jobs and distribute bed nets to the poor. Those are two metrics. We’ll agree on what are the targets over the next year or two years, and they’ll report back to us every quarter.

That’s an over-simplification; there’s not two metrics, there’s probably a dozen metrics. And obviously there’s not just one investment, there’s 30 investments. So you start seeing where this multiplies, and there’s really no kind of central organized way to do this across the portfolio.

Brian Trelstad, who’s the CIO at Acumen, is very much a quantitative person and thought this is not just applicable to what Acumen’s doing, but there’s a need for this in the sector, if we could use this system as a



means towards driving a conversation around identifying sets of standard metrics that people can agree upon to track. Then you could start doing that kind of reporting, whether it's aggregating your impact or benchmarking yourself against a set of peers. That really isn't possible today, the kind of thing that is taken for granted in traditional financial markets. "I want to invest in the stock market, I want to know all of the tech companies or some certain sector that has a growth rate of X" – anybody can do a report on Yahoo Finance or whatever and get that data and make decisions on where to put your money. You can't do that in the social investing space.

We've been having a lot of conversations around how do you do that, how do you even start. There's no governing body like the SEC [Securities and Exchange Commission] that says social investors must report X, Y, and Z. It has to be therefore more of a community-driven approach.

Our specific goal has always been around aggregation and benchmarking and developing a reporting engine. It would enable a potential investor who wants to give some of their own money to Acumen Fund or someone else to do the due diligence of seeing who's performing how. Academics could start to use this to write reports about what types of interventions work in a given space and what types don't and get more robust, meaningful data. I envision the potential consumers of this type of data to be across the gamut of anybody interested in social impact.

I think that there is potential for a lot more capital to flow to the space that's untapped, that is ready and potentially willing provided you can prove the effectiveness of your program, not just how efficient you are at operating but the actual social impact that you're creating.

FasterCures is engaged in a similar effort to create a marketplace for information about nonprofit disease research organizations through its **Philanthropy Advisory Service (PAS)** project, which aims to make it easier for philanthropists to align their goals and expectations with the capabilities of these nonprofits.

The obstacles to truly informed philanthropic investment in biomedical research are in many ways the same as for all social entrepreneurs:

- **Public information is not holistic.** Existing online services for evaluating charities typically focus on fundraising and administrative efficiency, not the actual effectiveness of these organizations in achieving their goals. They do not evaluate an organization's strategic approach, management, resource portfolio, or contributions to the field.
- **Purchased, specialized information is limited and not shared.** Philanthropists and foundations may engage more specialized philanthropy consulting services; however, the size of the donation must be sufficiently large to justify the cost of a consultant. Furthermore, those paying for their own strategic research and objective program evaluation generally do not share the information. As a result, every potential funder of a nonprofit who

is serious about accomplishing something is forced to replot the same ground.

- **There are no industry standards for nonprofit biomedical research.** Biomedical research is complex with a lengthy life cycle, and therefore measuring progress – especially in the nonprofit arena – is difficult. Without standards for evaluating disease research efforts, philanthropists are neither able to evaluate organizations in a meaningful way, nor compare organizations against one another or an industry benchmark. Thus, charitable investments are often given without appropriate understanding of the disease and the operations of those organizations managing research programs.

PAS – funded by the Gates Foundation and the Robert Wood Johnson Foundation – will offer reports on domestic and global diseases and the organizations researching therapies for these diseases. The disease reports will provide information such as disease burden and relative need, areas of research, commercial landscape, and nonprofit activities. The organizational reports will include information such as strategy and grants management process, research portfolio, management connectivity, governance functions, financial structure, and fundraising practices.

Additionally, *FasterCures* has developed a set of metrics to identify the practices and attributes of nonprofit disease research groups that we believe contribute to the acceleration of high-impact biomedical research towards cures for disease. A summary of these metrics is in Figure 3.

Figure 3: PAS Assessment Metrics

Operational Process	Accountability <ul style="list-style-type: none">Planning & monitoringMilestonesAdvisory BoardsIntellectual PropertyAccess & Delivery	Collaboration <ul style="list-style-type: none">Industry PartnershipsKnowledge-SharingTeam ScienceGlobal Research
Field Contribution	Research Effectiveness <ul style="list-style-type: none">Scientific AdvancementKnowledge ProductionPortfolio CongruencePipeline Profile	Resource Building <ul style="list-style-type: none">Tools/Resources Dev.Research TrainingPatient OrganizationClinical Trials Networks

The Myelin Repair Foundation (MRF), which funds a novel research collaboration in multiple sclerosis, has been more successful than most cure entrepreneurs at drawing the attention of mainstream and business media, as well as academia and consultants, to its model – in part because it has marketed the model itself, which it has dubbed the “Accelerated Research Collaboration,” as assertively as it has marketed its scientific efforts. The Robert Wood Johnson Foundation, which does not directly fund medical research, has funded MRF because it believes it offers a new research business model that can accelerate results in other disease areas.

Said MRF’s Chief Operating Officer Rusty Bromley at the *Esquire* meeting:

“In five years, we have had one philanthropic investor who has done diligence on us the way they would for a commercial investment. And we’ve had people give us millions of dollars that basically took it at face value. So I think there is a real need here in terms of educating people as philanthropic investors, because **this is a whole completely separate capital market, and it’s a capital market in which there are no rules.** I think we’ve got an opportunity to create a new rule set here that’s based on facts that are auditable by anybody who’s interested in taking the time to find out.”



Rusty Bromley talks about the importance of evaluating nonprofits.

V. Engaging the Wisdom of Crowds

Perhaps the most notable theme that threaded throughout our day at the *Esquire* event was the centrality of the needs, the perspectives, and the active engagement of the individuals whom a nonprofit aims to serve. In business this is sometimes called “crowdsourcing,” involving “consumers as creators” of products and services from T-shirts to furniture – to folded proteins that could help treat disease (<http://fold.it>).

In our interview with her, Victoria Hale reflected on another lesson from her work in global health that she feels has relevance to patient communities in the developed world. Critical to iOWH’s success, she believes, has been involving local communities – patients and healthcare providers – in their decisions about which therapies to pursue and how to deliver them.

“Communities and patients can be a driving force. They don’t know they can be. They have to be told that they can be. We’re used to this paradigm where companies just bring us products and then advertise to us. The communities need to be informed and need to be mentored in the fact that they can lead, and they can make decisions, and they can say no, and they can say we don’t want to participate in that clinical trial. They have a leadership role – not technical leadership, but leadership in terms of strategy and choices and decisions and selection. And informing and motivating and inspiring and teaching these patient groups to do this makes all the difference.”

At the *Esquire* meeting, Eva Guinan, Associate Professor of Pediatrics at the Dana-Farber Cancer Institute, echoed this sentiment:

“Patients are the only unique resource in the entire continuum. They can, by holding or yielding their consent to participate in any variety of activities along the various points to this enterprise, actually drive the entire thing. As that community is now awakening, much as the AIDS community did some decades ago, with the power that they hold, the process will change, because **they can create the ultimate bargaining unit.** You cannot do a cystic fibrosis experiment of any kind without the Cystic Fibrosis Foundation’s consent and support. It’s impossible. It does not matter who your money comes from, you can’t get to a sample.”

Elias Zerhouni, immediate past Director of the National Institutes of Health, now at the Gates Foundation, was unable to attend the meeting, but contributed his striking thoughts afterwards about what he views as the scientific imperative for greater patient engagement in the medical research process – not merely as subjects, but as decisionmakers.



Interview

Elias Zerhouni

Senior Fellow, Bill & Melinda Gates Foundation

Former Director, National Institutes of Health

There has been a decrease in productivity in terms of new molecules or new approaches to preventing and curing diseases over the past 15 years. I profoundly believe that the number one issue is a fundamental knowledge gap.



Our knowledge of biological systems is just so incomplete at this point that it is very difficult to be predictive about which target and how to affect the particular target in a molecular pathway or multiple pathways in a particular disease. I think our fundamental understanding of disease is changing and will have to change even more. It is very hard for scientists to always develop full and reliable models of a disease process in animal systems or cell systems, because there is no such thing as a simple disease, and human biology may have evolved differently from model systems, making animal models unreliable in guiding research, especially in common and complex diseases.

We need much closer ties between our basic research, our translational research, our clinical research, and our patients. Those ties have to be redesigned. Because at the end of the day, it is nice to understand the molecular pathway in the laboratory, it is nice to prove it by gene knock-outs or gene knock-in experiments in an animal model. But at the end of the day, unless you have access to and participation by a human population that can validate or invalidate your laboratory findings, then you have a problem. Because you will spend years and years and years researching targets which may be marginal targets in the disease process in humans.

The key thing here is to understand that you are not going to make progress unless you have a committed group of basic scientists, translational scientists, clinical researchers, and patient groups working together in a different way. Not in a subject-client relationship as we have seen in the past, but as true partners in research. I'm not saying that because it is socially correct or politically correct. I'm saying that because science will require it if it is to lower current barriers to progress. Because unless we have greater participation with lesser obstacles and costs it will be difficult to figure out these complex molecular pathways and these complex variability factors that I described as the number one issue that science is facing right now.

Patient groups have not realized yet what their more effective strategies should be. It is OK to argue for more money, do more research, and give it to the academic researchers. But at the end of the day, that is still an uncoordinated, dysfunctional system. It is not adding up to a very synergistic and more effective system because it does not engage enough the patients as active partners in accelerating the needed research.

The best research that I have seen has always come out from people who have access to long-term populations that are committed to the research process. The best examples are some foundations, like the Cystic Fibrosis Foundation, the Alpha-1 Foundation.

[The Alpha-1 Foundation] has gone into the integration pathway from healthcare delivery all the way to research. [CEO John Walsh] says "We want to be partners with the health insurance companies." They have a \$24 million contract to maximize healthcare for their patients, and it is costing less to the insurance companies. They're taking the proceeds from that to reinvest in the research and stimulate scientists to work on the alpha-1 antitrypsin problem. So, in other words, he has closed the circle. He is optimizing the management of the patient group, making it profitable for the health insurance companies to work with him. He is taking that margin and reinvesting it in research and then stimulating more research through NIH-funded grants, which he and researchers participate in together. I think this guy is very smart and may have pioneered a model to follow.

I think we need to invest much more money in basic research as we are still far away from having discovered key insights in our complex biology and its relationship to our evolving environment. But we need to also make much better use of our translational and clinical research than we do today, and that will require different organizational forms and a different “social” compact between patients and researchers based on more proactive strategies to remove the many bottlenecks in front of us.

Think as an example of the power of a true patient federation of Parkinson’s patients, with 300,000 participants out of the 1.5 million people that suffer here in the States, with a social network of scientists fully associated with them, jointly applying for trials at the NIH. As the former NIH Director, I know this would cost much less than what it is costing today, and it will give us potentially more and better science than what we are getting today.

There are breakpoints in the medical research system that can only be resolved by a strategic rethinking of the fundamental relationship between the patients, researchers, academia, government, and industry. The cure entrepreneurs can play the key role in bringing about such a revolution.

At the *Esquire* meeting, Harvard’s Lee Nadler appealed to the patient groups to bring their unique power to bear on changing the system:

“I’m wondering if you’re using enough of the force to actually make change. I hear each of you are beginning to work together, but you’re pretty

much working individually. I think the academic world that’s going to do the basic science and the pharmaceutical and biotechnology industry, they’re both threatened right now. I think they’re the most threatened they’ve been in as long as I can remember.

“How do we use you as that external force to bring us together to make that change? If we can put those voices together and use the advocacy groups and *FasterCures* to create a voice, maybe that word ‘collaboration’ and ‘interaction’ will become a reality. But right now I don’t hear a voice, I hear voices. So what’s the possibility?”

“There are three parts of the equation in a clinical trial. There’s who has control, who gets the reward, and who takes the risk. Patients take all the risk, they have no control, and they get no reward. Patients ought to be the ones driving the process and get the reward out of it and have the control, since they are the ones that take the risk.”

GREG SIMON

VI. Closing Thoughts

By Greg Simon

Social entrepreneurs and cure entrepreneurs represent the innovative edge of the new “passion capital” movement, as I like to call it.

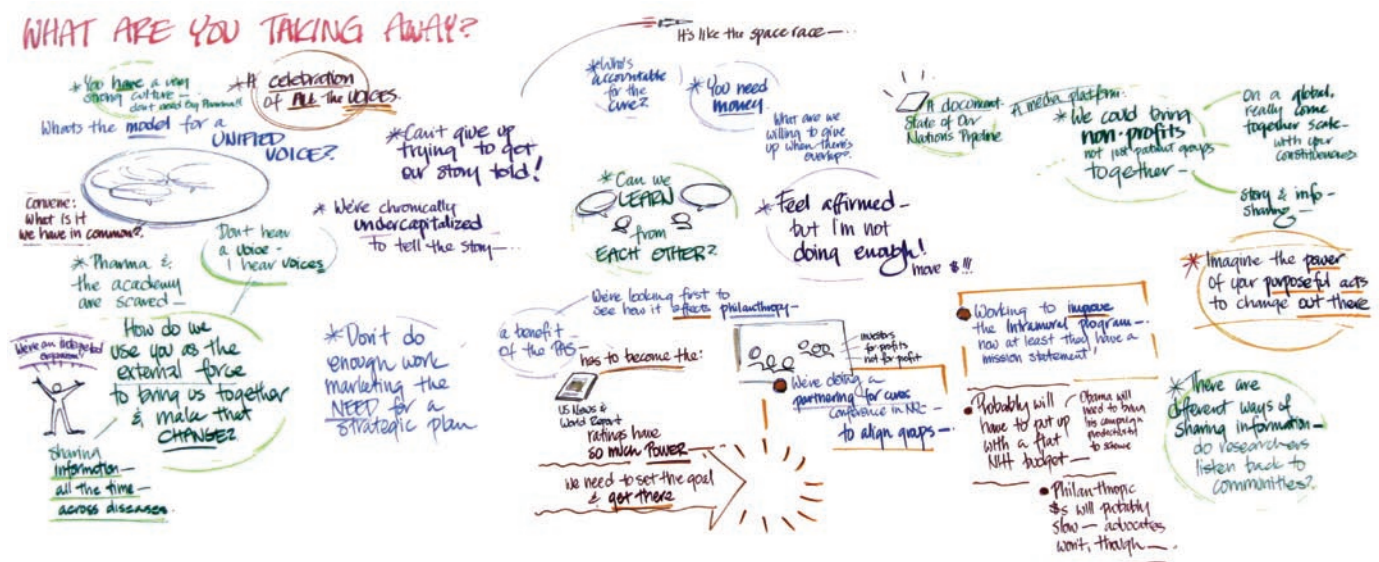
Social entrepreneurs do not think small thoughts. They aim not merely to serve people in need but to transform the dysfunctional systems that cause social problems. David Green, for instance, refers to what he does as no less than “humanizing capitalism.” In the words of Bill Drayton, CEO and Chair of Ashoka, “Social entrepreneurs are not content just to give a fish or teach how to fish. They will not rest until they have revolutionized the fishing industry.”

This is true of cure entrepreneurs as well. “Nonprofit research organization” cannot capture the emerging culture these new entrepreneurs have created. While social entrepreneurs work in places where you have to conquer nature, time, and space to improve health or deliver clean water, cure entrepreneurs live in small organizations that are fighting against the comfortable habits and familiar traditions that dominate medical research in order to create disruptive change in the interest of saving lives.

Our *Esquire* meeting gave us a chance to share the insights and experiences these innovators bring to their work, often with surprising – and moving – results. The intellectual and emotional resonance was one I will long remember. I hope this report gives you something to think about – and feel about – in your own life's work.

Thank you!

***FasterCures* would like to thank all our partners at *Esquire* magazine for their continuing support of our efforts to bring more innovation to the pursuit of medical research: David Granger, Kevin O'Malley, Stephen Jacoby, Dawn Sheggeby, and Jeff Chiaravanont. Thanks go as well to Kate Moulene of Capian Enterprises; Liam Lynch and Jack Connolly of Authentic Agency; and to graphic facilitator Tom Benthin, photographer Paul Bliese, and Blue Microphone's Tyler Barth for capturing the proceedings.**



VII. Appendix A

List of Meeting Participants

Margaret Anderson

Chief Operating Officer
FasterCures

Peter H. Bell

Executive Vice President
Autism Speaks

Karen Bergman

Founder and Partner
BCC Partners

Lucy Bernholz

Founder and President
Blueprint Research & Design, Inc.

Marisa Bolognese

Director of Planning and Development
The Life Raft Group

Rusty Bromley

Chief Operating Officer
Myelin Repair Foundation

Deborah Brooks

Co-Founder
Michael J. Fox Foundation for
Parkinson's Research

Timothy Coetzee

Executive Director
Fast Forward, LLC

Sharon Cohen

Senior Fellow
The Philanthropic Initiative

Sophia Colamarino

Vice President, Research
Autism Speaks

Joyce Cramer

President
Epilepsy Therapy Project

A. Stephen Dahms

President and Chief Executive Officer
Alfred E. Mann Foundation for
Biomedical Engineering

Jesse Dylan

Director, Producer

Patricia Finneran

Senior Consultant
Engaged Entertainment

Joan Flax

Co-Founder
California Pizza Kitchen

Larry Flax

Co-Founder
California Pizza Kitchen

Rick Franklin

Founder and Chairman
DMS Data Systems

David Green

Vice President
Ashoka

William Greene

General Partner
MPM Capital

Eva C. Guinan

Associate Professor of Pediatrics
Dana-Farber Cancer Institute

Victoria Hale

Founder and Chair Emeritus
Institute for OneWorld Health

Melodie Holden

Senior Vice President/Chief Operating Officer
Venture Strategies for Health and Development

Jason Hwang

Executive Director, Health Care
Innosight Institute

Catherine Ivy

Founder
The Ben and Catherine Ivy Foundation

Hannah Kettler

Program Officer, Global Health Policy and Finance
The Bill & Melinda Gates Foundation

Michael Klowden

President and Chief Executive Officer
Milken Institute

Jim Kovach

President and Chief Operating Officer
Buck Institute for Age Research

Carol Lin

Chief Executive Officer
TulaHealth

Peter T. Lomedico

Strategic Alliances & Industry Partnerships
Juvenile Diabetes Research Foundation

Michael Milken

Chairman
FasterCures

Lee M. Nadler

Senior Vice President, Experimental Medicine
Dana-Farber Cancer Institute

Nancy Patterson

Vice President
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Biomedical Engineering

Kyle Peterson

Managing Director
FSG Social Impact Advisors

Marcia F. Ritchie

Vice President and Chief Operating Officer
Alpha-1 Foundation

Norman Scherzer

Executive Director
The Life Raft Group

Greg Simon

President
FasterCures

Jonathan Simons

President and Chief Executive Officer
Prostate Cancer Foundation

Warren Thaler

President
Gund Investment Corporation

Michael P. Walsh

Founder and Managing Partner
Kilkenny Capital Management, LLC

John Wilbanks

Executive Director
Science Commons

Betsy Zeidman

Director, Center for Emerging Domestic Markets
Milken Institute

Appendix B

Fast Company Magazine's Social Capitalist Awards 2004-2008

A Fighting Chance	KIPP Foundation
A More Powerful Path	Mercy Corps
ACCION International	MicroBusiness Development Center
Acumen Fund	Network for Good
ApproTEC	New Community Corp.
Aspire Public Schools	New Leaders for New Schools
BELL (Building Educated Leaders for Life)	New Leaf Paper
Benetech	The New Teacher Project
Benhaven	Nonprofit Finance Fund
Better World Books	Organic Valley Family of Farms
Calvert Social Investment Foundation	PATH
Center For Community Self-Help	Peaceworks Foundation
Ceres	Pioneer Human Services
Citizen Schools	Points of Light Foundation & HandsOn Network
City Year	Population Services International
Civic Ventures	PSI
Civic Builders	Public Allies
College Summit	Raising a Reader
Common Ground	Rare
Community Reinvestment Fund	Reach Out and Read
Corporation for Supportive Housing	Room to Read
Developing World Markets	Root Capital
Domini Social Investments	Rubicon Programs Inc.
DonorsChoose.org	Scojo Foundation
EARN	SEED Foundation
EcoLogic Finance	Seventh Generation
Endeavor Global	Share our Strength
Equal Exchange	ShoreBank
First Book	Social Venture Partners
Global Fund for Women	Springboard Forward
Grameen Foundation	SustainAbility
Hands On Network	Teach for America
Heifer International	TransFair USA
Herman Miller	Unitus
Housing Partnership Network	Vera Institute of Justice
IFF	Verite
Jumpstart	Witness
KaBoom	WorkingToday Freelancers Union
KickStart International	Year Up

Appendix C

Sample of Social Entrepreneurship Organizations/Resources

A small sample of organizations representing the depth and breadth of the human, intellectual, and financial capital that is being brought to bear on social entrepreneurship.

Investment Funds

Acumen Fund
Calvert Social Investment Foundation
Developing World Markets
Good Capital
New Profit, Inc.
Nonprofit Finance Fund / NFF Capital Partners
REDF (formerly Roberts Enterprise Development Fund)
Root Capital
Sea Change Capital
Social Venture Partners
Venture Strategies

Foundation Funders

Ashoka
Bill & Melinda Gates Foundation
Schwab Foundation for Social Entrepreneurship
Skoll Foundation

Consulting Firms

FSG Social Impact Advisors
Monitor Institute
SustainAbility
Social Venture Technology Group
Virtue Ventures

Market Intermediaries

Altruistiq Exchange
KLD Research & Analytics
Mission Markets
Social Funds
Xigi.net

Membership Associations

Business for Social Responsibility
Social Investment Forum
Social Venture Network

Academic/Think Tanks

Center for the Advancement of Social Entrepreneurship, Duke University
Center for Social Innovation, Stanford University
Center for Venture Philanthropy
Hauser Center for Nonprofit Institutions, Harvard University
Nonprofit Sector and Philanthropy Program, Aspen Institute
Social Enterprise Initiative, Harvard Business School

Publications/Communications

Changemakers.net
Fast Company Social Capitalist Awards
Philanthropy 2173 blog
Socialedge.org
Stanford Social Innovation Review
Sundance Institute "Stories of Change"
Tactical Philanthropy blog

Performance Measurement Tools

Global Reporting Initiative (Ceres)
Keystone initiative (formerly ACCESS, www.accountability.org.uk)
Pulse (formerly Portfolio Data Management System)
Social Solutions

Online Giving Marketplaces

Donors Choose
GiveMeaning
GlobalGiving
Kiva
NetworkForGood

Events

Skoll World Forum
Social Capital Markets

Appendix D

Recommended Reading

Cure Entrepreneurs

FasterCures/The Center for Accelerating Medical Solutions. 2008. *Entrepreneurs for Cures: The Critical Need for Innovative Approaches to Disease Research*. Washington, DC: FasterCures/The Center for Accelerating Medical Solutions.

Herper, Matthew. "Patient Power," *Forbes*, September 15, 2008.

Social Entrepreneurs

Alvord, Sarah H., L. David Brown, and Christine W. Letts. 2002. *Social Entrepreneurship and Social Transformation: An Exploratory Study*, Harvard University: Hauser Center for Nonprofit Organizations.

Center for the Advancement of Social Entrepreneurship. 2008. *Developing the Field of Social Entrepreneurship*, Duke University: Fuqua School of Business.

Hammonds, Keith H. "A Lever Long Enough to Move the World," *FastCompany*, December 19, 2007.

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SustainAbility. 2007. *Growing Opportunity: Entrepreneurial Solutions to Insoluble Problems*, London: SustainAbility.

Intellectual and Financial Capital

Bailey, Elizabeth, Meg Wirth, and David Zapol. 2005. "Venture Capital and Global Health," a discussion paper prepared for the September 2005 workshop "Financing Global Health Ventures," organized by Commons Capital and CIMIT/MAP. http://www.commonscapital.com/downloads/Venture_Capital_and_Global_Health.pdf.

Berenbach, Shari, Laura Callanan, and Kevin Jones. 2008. "Making Sense of the Social Capital Landscape: Defining a Common Language," prepared for the SOCAP08 Conference. <http://socialcapitalmarkets.net/files/Social-Capital-Landscape.pdf>.

Christensen, Clayton M., Jerome H. Grossman, and Jason Hwang. 2009. *The Innovator's Prescription: A Disruptive Solution for Health Care*, New York, NY: McGraw-Hill.

Elkington, John and Pamela Hartigan. 2008. *The Power of Unreasonable People: How Social Entrepreneurs Create Markets That Change the World*, Boston, MA: Harvard Business Press.

Emerson, Jed, Tim Freundlich and Jim Fruchterman. 2007. *Nothing Ventured, Nothing Gained: Addressing the Critical Gaps in Risk-Taking Capital for Social Enterprise*, University of Oxford: Said Business School.

Measuring, Maximizing, and Marketing Progress

FSG Social Impact Advisors. 2007. *Toward a New Approach to Product Development Partnership Performance Measurement*, Boston, MA: FSG Social Impact Advisors.

Hamm, Steve. "Tracking 'Social Entrepreneurs' Gets Easier," *Business Week*, September 25, 2008.

Kramer, Mark R. 2005. *Measuring Innovation: Evaluation in the Field of Social Entrepreneurship*, Boston, MA: Foundation Strategy Group.

Trelstad, Brian. 2008. "Simple Measures for Social Enterprise," *innovations*, 3(3).

FasterCures is dedicated to saving lives by saving time. Our mission is to identify and implement global solutions to accelerate the process of discovery and clinical development of new therapies for the treatment of deadly and debilitating diseases. ***FasterCures*** was formed under the auspices of the Milken Institute.



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FasterCures
1101 New York Ave, NW Suite 620
Washington, D.C. 20005
(202) 336-8900
www.FasterCures.org